## Maryland Early Hearing Detection and Intervention (MD EHDI) Advisory Council

Minutes July 21, 2016

# **Members Present**

Jennifer Reesman, PhD, Chair Claire Buxton, AuD, Vice Chair Judith Black Bridgetta Bourne-Firl Lori Moers Jessica Thornton Sue Burnes Stacy Fitzgerald

## **Members Absent**

Kelby Brick Brian Reilly, MD Olga Polites

#### Staff

Ilise Marrazzo Donna Harris Erin Filippone Tanya Green (scribe) Brianna Creed

#### Guests

Ben Dubin, Past Chair
Sue Griebler, Past Chair
Louise Colodzin, Past Vice Chair
Cheri Dowling, Past Parent Member
Cecilia Ward
Marny Helfrich
Kaycee Reese
Allysa Dittmar
Richard Jeffries
John Sloan
Dawn Marsiglia

# Called to Order - 12:45PM

#### I. Welcome Introductions

- Members, Maryland Department of Health and Mental Hygiene (DHMH) staff, and guests introduced themselves.
- Sharing of Story Dr. Jennifer Reesman shared a story about a 10 year old Pennsylvania boy who had special needs and had a detrimental experience while in the foster care system.

#### **II. Previous Minutes**

Board members received the minutes for review prior to today's meeting.

- Minutes of the November 12, 2015 meeting were approved as circulated.
- Minutes of the January 21, 2016 meeting were approved as circulated.
- Minutes of the April 21, 2016 meeting were approved as circulated.

## **III. Old Business**

Stacy Fitzgerald (Maryland State Department of Education (MSDE)
representative) to provide information on MSDE's policies at the statewide level
for children who are deaf or hard of hearing and what MSDE expects from the
local jurisdictions

- Lori Moers (Maryland School for the Deaf (MSD) representative) to provide information on MSD's policies regarding steps taken when a family is referred to them
- MD EHDI Advisory Council Motion (Donna Harris)
   The motion from the MD EHDI Advisory Council has been received from Dr.
   Reesman [on Thursday, July 14, 2016] and is with the Secretary of DHMH and we are awaiting a response. A number of stakeholders have called and sent letters to express their opinion not in support of the motion.

Dr. Reesman stated she attended a meeting with DHMH and Governor's Office of the Deaf and Hard of Hearing (ODHH) where it was requested that she, as Chair of the Council, provide a letter to DHMH on the motion. Judy Black asked Dr. Reesman if she attended the meeting as Chair of the MD EHDI Advisory Council and if any council member was made aware of the meeting. Dr. Reesman stated she was invited by Kelby Brick to attend the meeting and confirmed that the Council was not informed of her attendance.

Ilise Marrazzo, director of the Maternal and Child Health Bureau at DHMH stated that after Kelby posted the motion on the ODHH Facebook page, the DHMH received numerous phone calls and emails. DHMH requested a meeting through the Governor's Office with Kelby to obtain clarity and request that the information be removed from Facebook, however the Facebook post has not been removed or revised. Ilise informed the Council of three possible outcomes that the DHMH Secretary may choose in response to the motion: (1) to agree with the motion (2) to disagree with the motion (3) to establish a workgroup of individuals and experts to formulate research components, to look at what other states are doing, to solicit public comments, to identify all stakeholders and how they may be impacted by the motion, and to determine the feasibility of implementation. Ilise further stated that from her personal and professional experience, option 3 may be more likely, however, ultimately it will be the Secretary's decision. Ilise added that DHMH would interface directly with Dr. Reesman as Chair and Dr. Reesman would decide who from the Council would be involved, and share information with the Council.

Judy Black expressed the following 5 concerns:

- 1. The motion requested was not on the agenda and not all board members were in attendance.
- 2. The motion was brought up in the middle of the planned agenda.
- 3. The motion was written by one member of the Council.
- 4. Two members asked for more time to discuss to table the motion but both requests were not acknowledged.
- 5. I would like to ask for a revote electronically so that all council members can have a vote.

Bridgetta Bourne-Firl expressed the following concerns:

- 1. The council is current consisting of various representatives in attendance ranging from educators to parents to organizations and I advised that the Department of Health take our actions and recommendations into serious consideration and consider them valid. Why would they need to establish a separate committee when we are already a group of representatives knowledgable about EHDI issues, challenges, and concerns?
- 2. I advised the Department of Health to take a closer look at the phone calls/letters they received to see what special interest they represent if any? Are those who have written/expressed concerns in the field and/or knowledgeable when it comes to working with families and babies age 0-3? They should be weighted to measure validity -- enough to put the council's formal recommendation that was voted upon to be put "aside" and almost disregarded?

\*Note: After the meeting, Bridgetta emailed clarification of her statements.

New Member Orientation Materials
 It was moved by Judy Black and seconded by Sue Burnes that the orientation materials be re-sent to board members for review and orientation materials will be voted on at the next meeting. Any questions should be emailed to Tanya, Dr. Reesman and Dr. Claire Buxton or reply all to the email.

# IV. Membership Update (Tanya Green)

- There is one vacancy. The DHMH member position was left vacant when Dr. Cheryl De Pinto resigned on May 19, 2016. DHMH is actively seeking to fill this position.
- The following member terms were renewed for July 1, 2016 June 30, 2019:

Stacy Fitzgerald (MSDE)
Judith Black (Educator from a Local Education Agency)
Bridgetta Bourne-Firl (Maryland Association of the Deaf)

## V. MD EHDI Program Update

- The MD EHDI Program currently has 3, full-time six month temporary employees who began during March, 2016 to assist with follow up of babies who missed or were referred for further testing at the time of their birth hearing screen.
- The Health Resources and Services Administration (HRSA) goal for reducing loss to follow up/documentation is 20% or below. This goal has been achieved with a loss to follow up/documentation rate of 19%.
- A Centers for Disease Control and Prevention (CDC) award was recently granted for an additional year of funding to be used to enhance the data system used by the MD EHDI Program.

- The New York Mid-Atlantic Consortium (NYMAC) will hold a summit in Baltimore on October 4<sup>th</sup> and 5<sup>th</sup>, 2016 entitled, "NYMAC Bridging the Gaps in Genetic and Newborn Screening Services". Registration is free. Tanya may be contacted for additional information.
- NYMAC will conduct a survey of pediatricians, family practice physicians, nurse
  practitioners, and physician assistants to learn more about the knowledge and
  practices of health care providers regarding genetic services for infants and
  young children who are deaf or hard of hearing. The survey will be conducted
  soon so that the results can be analyzed and presented on at the October, 2016
  summit.

## VI. MD EHDI 2016 Stakeholders Meeting Update (Cheri Dowling)

 The May, 2016 MD EHDI Stakeholders Meeting had a record number of 115 attendees. The evaluations were overwhelmingly positive.

## VII. Parent Connections Update (Cheri Dowling)

• The Parent Connections parent to parent mentor program has received renewed funding from the Office for Genetics and People with Special Health Care Needs/DHMH for the next three years. A minimum of four events will be provided for families next year. The MD EHDI Stakeholders Meeting is included in the funding. The next event is the Family Learning Weekend which will be held in September, 2016. The focus of will be on and inclusive of students and families around the topic of transition.

# <u>VIII. Newborn Hearing Screening Protocols Best Practices Workgroup Update (Dr. Claire Buxton)</u>

 A draft of the protocols document was handed out. Claire requested additional support from the council on some of the sections in the document that still need to be filled in. Tanya will fill in the introductory information and will add legislative information to include the statute and regulations.

## IX. New Business

 Maryland Open Meetings Act Training – Tanya and former member, Mary Ann Richmond have completed the Open Meetings Act training. Tanya will email the training link to board members.

## X. Announcements

Judy Black provided copies of two articles:
 "Parents of Deaf Children, Stuck in the Middle of an Argument" by Tina Donvito, May 24, 2016; New York Times
 "Refocusing Choices" by Elizabeth Thompson Beckley, May, 2016 Vol., The ASHA Leader

• Bridgetta recently conducted a webinar entitled, "Maximizing Language Acquisition: ASL and Spoken English". She will email the webinar link to Council members.

# XI. MD EHDI Data System Demo (Erin Filippone)

## XII. Adjournment

• The Chair adjourned the meeting at 2:45PM. The next meeting will be held on Thursday, October 20, 2016 at the Hearing and Speech Agency from 12:30PM to 2:30PM (park in the rear lot).